



Research

Education

Support

Advocacy

Awareness



**PKD FOUNDATION**  
Polycystic Kidney Disease

July 1, 2014—June 30, 2015

**FY15 ANNUAL REPORT**

# Thank you for an incredible year

The Foundation surged forward last fiscal year in many ways, bringing us closer to treatments, providing support and resources for more people, and advancing the PKD cause on Capitol Hill. We rely completely on private donations to fund the critical work of the Foundation's mission, and the generosity of dedicated supporters made the accomplishments in this report possible.

## Highlights include:

- ▶ Five newly funded fellowship recipients were introduced.
- ▶ New Chief Scientific Officer David Baron, Ph.D. was welcomed.
- ▶ New *PKD Patient Handbook* was published.
- ▶ Estate Planning Guide was produced.
- ▶ The PKD Connection blog was launched.

The success of last fiscal year sets us up for even greater success in the future. With this momentum, we'll continue gaining speed, investing in new research pointed toward potential therapies, and adding value to programs and Chapters.

We can't do this work without you and we are grateful for all you do to keep us moving forward. Thank you for your unflagging support!

Sincerely,



Benjamin D. Cowley, Jr., M.D.  
PKD Foundation Board Chair



Jackie Hancock, Jr., CFRE  
PKD Foundation CEO



# YOU'RE ADVANCING RESEARCH

## \$40 million

Since its founding in 1982, the PKD Foundation has invested more than \$40 million in research, clinical and scientific grants, as well as fellowships and scientific meetings on an international scale, making us the second largest funder of PKD research in the U.S. after the National Institutes of Health (NIH).

This has led to new discoveries about PKD, including identifying the genes responsible for PKD, which enables researchers to investigate possible treatments.

**PKD FOUNDATION AMONG TOP 30 GRANT GIVING  
DISEASE FOUNDATIONS (UP TWO SPOTS FROM 2014)**



by Genetic Engineering and Biotechnology News (GEN)  
for percent of revenue spent by a nonprofit disease  
foundation on research grants and awards

# Fellowships

Investing in fellowships is a vital element of our research mission that your support makes possible. In 2015, the Foundation announced five newly funded Foundation Fellowships recognizing early-career scientists whose achievements and professional potential identify them as rising stars - the next generation of scientific leaders in PKD research. Each fellow received \$50,000 a year for two years, a research investment of a half-million dollars.

The success of the 2015 Matching Gift Challenge made it possible for the Foundation to fund five Fellowships rather than three, our initial goal. Through this challenge, gifts between May 1 and June 30 raised nearly \$252,000 from individuals. Combined with \$160,000 in match funds from dedicated friends of the Foundation, nearly \$412,000 was raised.

# Grants

Thanks to the generosity of our donors, in 2014 and 2015 the Foundation invested \$1.2 million each year to fund 15 research projects selected for their promise in developing diverse new strategies to treat ADPKD and ARPKD.



Visit [pkdcure.org/research/grants#2014-grants](http://pkdcure.org/research/grants#2014-grants) for a progress update.



## Grant recipient focused on potential treatment

Irfana Soomro, MBBS, is a clinical instructor in the division of nephrology at New York University Langone Medical Center, Bellevue Hospital Medical Center. Her research targets inhibiting glutamine metabolism as a potential treatment for ADPKD. She is grateful for the fellowship she was awarded. "It's not only a prestigious award to receive, but it allows me the opportunity to continue research in the PKD field."

Under the mentorship of Edward Skolnik, M.D., director of the Division of Nephrology, Dr. Soomro hopes to continue on a physician/scientist track. "Research helps me better understand the mechanisms of the disease at the molecular level, which may also aid in treating PKD patients."

### Fellowship recipients:

**Jeong-In Baek, Ph.D.,**  
Medical University of South Carolina

**Whitney Besse, M.D.,**  
Yale School of Medicine

**Marcelo Cassini, M.D., Ph.D.,**  
Yale School of Medicine

**Jacqueline Peda, Ph.D.,**  
University of Kansas Medical Center

**Irfana Soomro, MBBS,**  
New York University Langone  
Medical Center

In addition to the Matching Gift Challenge donors, these fellows are grateful to the following who stepped forward to provide significant underwriting support for fellowships.

**The Lillian Goldman Charitable Trust**  
**The Island Foundation**

"I am truly thankful for this opportunity and hope to make meaningful contributions in the PKD field of research."

—Irfana Soomro, MBBS



## Funding from Foundation grant sustains critical research

Vishal Patel, M.D., has been able to sustain his NIH research, thanks to a significant funding gap bridged by the PKD Foundation. The PKD Foundation grant helped him maintain momentum on research that was used as preliminary data in applications to NIH to further explore his findings.

“I’m grateful the PKD Foundation found the idea interesting enough to fund. That support could not have come at a better time.”

—Vishal Patel, M.D., University of Texas Southwestern Medical Center

Researchers and patients are grateful to the following who stepped forward to provide significant underwriting support for these 15 research grants.

**Estate of Eileen Creamer O’Neill**

**Friends and Family of Infant Sophie St. Aubin**

**KidneyTexas, Inc.**

**The Carlo and Micol Schejola Foundation**

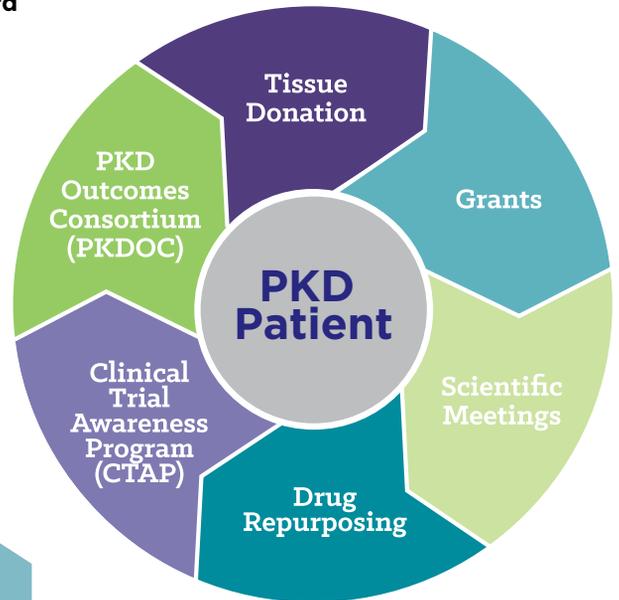
**The Pamela Whitcomb Larsen Foundation**

**The Whitcomb Charitable Foundation**

**Anonymous support in recognition of Jean A. Bost**

**The Rosemary M. Peppet Award**

**The Haggard Family Award**



Visit [pkdcure.org/research](http://pkdcure.org/research) to stay up to date on the PKD research activities you are making possible!



# YOU'RE PROVIDING EDUCATION AND SUPPORT

The PKD Foundation is the go-to resource for support and education on living with PKD and dialysis and transplant alternatives when a patient's kidneys fail.

Patients and their loved ones turn to us when they have questions and are able to get answers, at no cost to them, thanks to your generous support. Offerings include webinars, videos, a multi-faceted website with online communities and print resources.

**Visit [pkdcure.org/learn](http://pkdcure.org/learn)**

Local education and support in more than 60 Chapters across the country bring the mission to life by ensuring that no one faces this disease alone.

These Chapters are entirely led by volunteers passionate about making a difference in the lives of PKD patients and their families on a grass roots level.

**103,639**

visits to PKD Connection blog

**1,307**

information packets distributed

**9** webinars with

**1,267** participants

**122** Chapter education and support events

**PKD**  
**CONNECTION**

# Local and Virtual Chapters

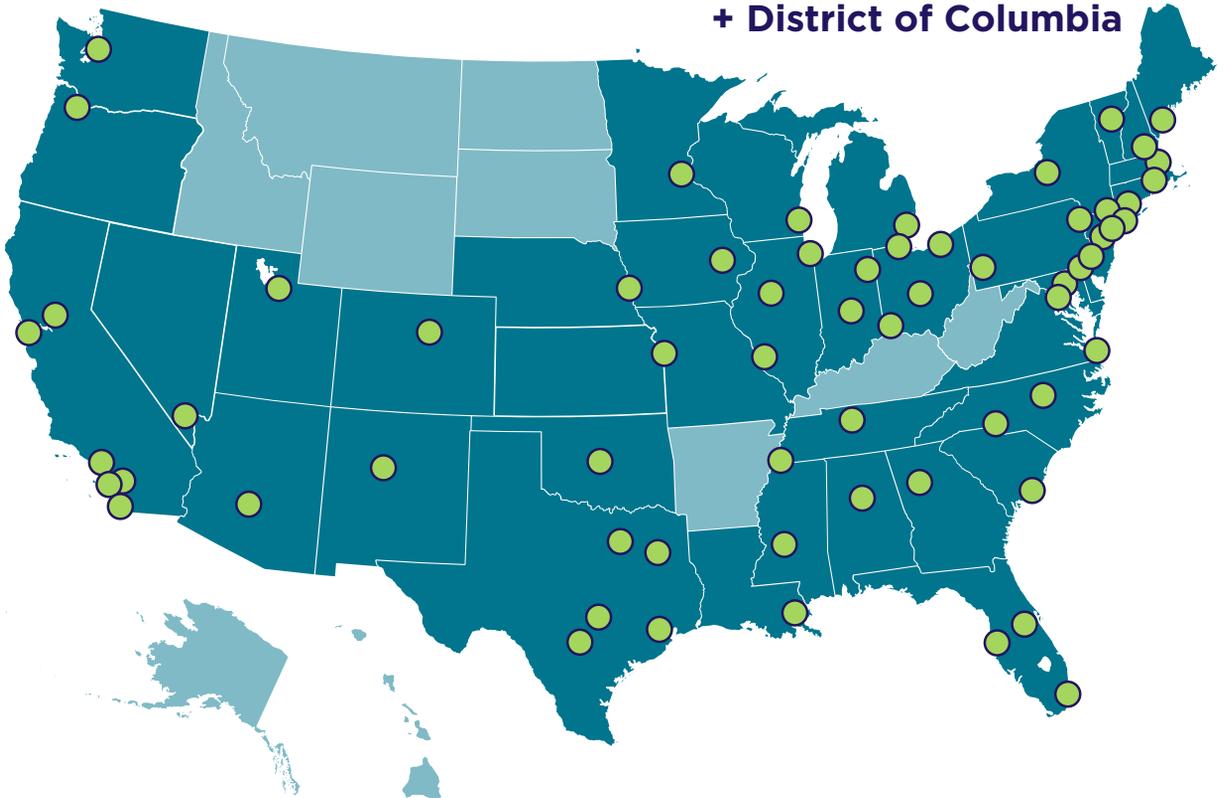
Local education meetings provide valuable information from health care professionals, while support activities range from lending a listening ear to organized meetings. Virtual Chapters help the Foundation meet the needs of patients in cities where the Foundation doesn't have a local presence. The PKD Parents Chapter connects parents of children with both ARPKD and ADPKD for education, support and resource sharing.



[pkdcure.org/connect/chapter-locations](https://pkdcure.org/connect/chapter-locations)

Over **60** volunteer-led Chapters  
across the country in **40** states

+ District of Columbia



“I really appreciate the PKD support meetings. They give me the chance to learn from others and their experiences with PKD and ask questions to be sure I understand how it applies to my PKD. It is a great relief and comfort. I always feel better when I leave.

– Glen Kemper, St. Louis Chapter

# Webinars

Throughout the year, nine webinars drew an audience of more than 1,200 participants. Among the most popular webinars were the “Kidney Allocation System Q & A” and “Preimplantation Genetic Diagnosis (PGD) 101.” The kidney allocation webinar featured Clifford Miles, M.D., UNOS Kidney Transplantation Committee Region 8 Representative, who addressed the Organ Procurement and Transplantation Network’s (OPTN) new system for allocating deceased donor kidneys. The PGD webinar was presented by Lawrence Grunfeld, M.D., clinical associate professor of Obstetrics and Gynecology at the Mount Sinai School of Medicine. Other topics included nutrition, the HALT PKD study, PKD pain management and an update on the Foundation’s Accelerating Treatments to Patients research program by new Chief Scientific Officer David Baron, Ph.D.

# Education

Your support also helped fund What’s New in PKD: A Day of Learning - an online, interactive virtual education conference presented through local PKD Chapters across the United States free of charge. Presentations by some of the nation’s preeminent PKD experts focused on complications associated with PKD, including aneurysms, hypertension, cardiovascular issue, cardiac valve abnormalities and polycystic liver disease.



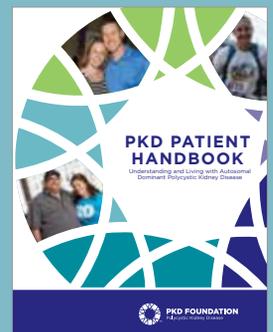
Visit [pkdcure.org/learn/multimedia/webinars](http://pkdcure.org/learn/multimedia/webinars) to view the webinars.



The PKD Connection blog provides the PKD community a place to gain tips to proactively manage their or a loved one’s

health and have a conversation with other PKD patients and families.

A new *PKD Patient Handbook* was published for those with autosomal dominant polycystic kidney disease (ADPKD), to help them navigate their disease. We’re grateful to the education grant from Otsuka America Pharmaceutical, Inc. for making this handbook possible.



Request a handbook at [pkdcure.org/patienthandbook](http://pkdcure.org/patienthandbook)



# YOU'RE ADVOCATING

Partnered with **16** kidney organizations for **2** advocacy days on Capitol Hill, involving nearly **250** advocates

A robust advocacy program targets members of Congress locally and through partnerships with leading kidney organizations to spread the word about PKD on Capitol Hill. The PKD Advocacy Action Center provides resources or people to advocate, and the Foundation sends Advocacy Alerts for legislative and public policy issues impacting PKD patients and families.

PKD advocates attended more than 150 meeting with members of Congress on Capitol Hill.

- ▶ **Kidney Patient Summit hosted by the National Kidney Foundation (NKF)**
- ▶ **Rare Disease Day hosted by Legislative Advocates with a focus on Autosomal Recessive PKD (ARPKD), a rare genetic disorder that can cause significant mortality in the first months of life.**

# Advocacy: From heartbreak to healing



Keith and Kristen Neary's daughter, Helen Grace, didn't survive long in the world, but her life has had a major impact. Diagnosed with autosomal recessive PKD (ARPKD) when Kristen was 28 weeks pregnant, Helen Grace lived just 34 hours. ARPKD is a relatively rare form of PKD, affecting approximately one in 20,000 children. Since that devastating time, the Nearys have made sure Helen Grace's life was honored by raising funds and awareness.

The Nearys were among the first group of advocates from the PKD Foundation to participate in Rare Disease Week on Capitol Hill to educate legislators.

"For critical legislation to pass, it is integral for us to tell our individual stories so that it becomes real to our representatives. I'm glad I had an opportunity to take part in Rare Disease advocacy work and hopefully make a difference."

– Kristen Neary

## 21st Century Cures Bill

PKD Foundation provided tools and training to its advocates to help them communicate our legislative priorities, including the U.S. House of Representatives 21st Century Cures legislation. The bill aims to spur biomedical innovation, change the way federal health officials approve drugs and medical devices and increase research funding for the National Institutes of Health.

### Duo unite to fight for PKD on Capitol Hill

Liz Casperite – a longtime PKD advocate – and her kidney donor Maria Weaver-Hollowniczky are making it their personal mission to spread the word about the need for more living kidney donors. One week before their transplant surgery, they teamed up with other PKD Foundation patients and volunteers for Kidney Community Advocacy Day on Capitol Hill to meet with members of Congress to raise awareness, promote increased support for kidney research funding and request co-sponsorship for the Living Donor Protection Act, a bill that would protect the rights of living organ donors. "Liz and I hope increase kidney donations through advocacy in the coming years. We have only just begun!"





# YOU'RE INCREASING AWARENESS

**More than 85,000 people** subscribed to receive emails from the Foundation.

Raising awareness is a key element in our mission to support, educate and fund research. We're committed to boosting awareness about PKD through marketing and public relations, social media, our monthly e-newsletter PKDnews and blogs, discussion forums and PKD Progress magazine.





# YOUR GENEROSITY

Donations of more than  
**\$8.03 million**

Your financial commitment makes the work that the PKD Foundation does to end PKD possible. We are 100 percent reliant on private donors to continue our work - we receive no government or public support. Your generosity led to donations of more than **\$8.03 million** in fiscal year 2015.

**31,179 gifts from 50 states, the District of Columbia and 25 countries were made**, with each donor giving **\$318** on average.

More than **13,000 people made their first gift to the PKD Foundation last year**, and **2,629 increased their gift from the prior year**, a sign of their confidence in our work.

# Foundation Partners

Foundation Partners are leadership donors from our three giving societies:

► **Founders' Annual Giving Society**

(donors who contributed at least \$1,000 within a year)

► **Lifetime Giving Society**

(individuals, corporations and foundations who have made significant investments of at least \$100,000 to the Foundation over their lifetime)

► **PKD Legacy Giving Society**

(members investing in the PKD Foundation through their will or other estate plans, creating a lasting legacy in the fight to end PKD)

Estate gifts (otherwise known as bequests) of \$1.18 million were received from the following donors in fiscal year 2015. Special thanks to these individuals for their commitment to continuing the work of the PKD Foundation.

Judith E. Bryer

Raymond Cabadas

Jim M. Carnes

Gerald Preston Clancey

Laura B. Culberg

Edith M. Fath

Pauline D. Gotay

Marianne M. Hudec

Margaret A. Jones

Edith M. Key

Carole Lundberg

Estate of Eileen Creamer O'Neill

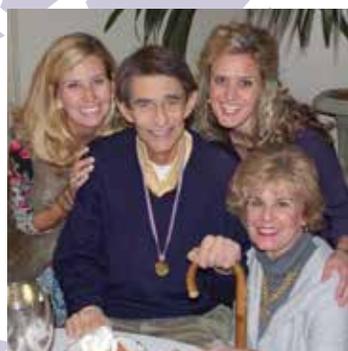
Diane J. Weber

Julia L. Wilson

To help you understand your gift planning options, the Foundation published a new Estate Planning Guide. The guide helps you review your final instructions to make sure they reflect both your current wishes and the recent developments in tax laws.



Email [estategiving@pkdcure.org](mailto:estategiving@pkdcure.org) to receive a copy.



"Kai was a fighter to the ultimate degree. There was no end to what he would endure for the cause. He was our family's guiding light, and we wanted his memory to be honored."

– Toni Kaiser, Wife of Kai Kaiser

## Fighting spirit lives on through Kai Kaiser Tribute fund

For more than three decades, Kai Kaiser faced his PKD with courage, optimism and a fighting spirit, ultimately losing the battle in March 2015.

To honor his memory, the family set up a Tribute fund in his name at the PKD Foundation. Family and friends of the Kaisers gave \$8,170 in honor of Kai.

"Kai was a fighter to the ultimate degree," says his wife of 37 years, Toni. "There was no end to what he would endure for the cause. He was our family's guiding light, and we wanted his memory to be honored."

More than a loving tribute, the fund is the family's way to contribute in a productive and meaningful way.

"Kai would be flattered and honored about the fund – and extremely hopeful that the dollars donated in his memory would make a difference for many!" says Toni.

# Events

## Walk for PKD

This signature fundraising and public awareness event is the largest gathering of PKD patients and supporters.



54  
walks

Raised  
**\$2,029,246**

Over  
**10,000**  
participants

Nearly  
**1,000**  
Volunteers



## Run for PKD

This endurance fundraising program engages athletes across the country through marathons, half-marathons, 5Ks, triathlons and more. The Run for PKD raised **\$149,631, from 1,467** donors through **72 races and 123** PKD runners.

## Chapter Events and DIY for PKD

Through these events passionate individuals can 'fundraise their way' to help raise money to end polycystic kidney disease. A total of **97** individuals organized fundraising activities that raised **\$421,652**.

We are grateful to those that organized and participated in these events that raised **\$5,000** or more:

Memphis Driving  
Home a Cure \$96,296

Kidney Casino  
for a Cure \$81,358

Turpin Sisters Golf  
Tournament \$48,060

Celtic Marketing Golf  
Tournament \$29,332

Hudson Valley Cocktails  
for a Cure \$16,665

Carson's Creekside  
Golf Tournament \$15,175

Ella Grace Race \$6,650

Callan Taylor Golf  
Tournament \$6,500

## Dallas Gratitude Benefit

The second annual Gratitude: A Celebratory Benefit for the PKD Foundation held in Dallas in Feb. 2015 raised \$115,000 and honored those who have made a considerable impact on the Foundation through fundraising, philanthropy, volunteerism, patient care and research. Our thanks to honorary chairs Klee and Brigid Kleber and event chairs Betsy and Chris Cook.

Congratulations to honorees:

KidneyTexas, Inc. of Dallas, Philanthropist

The Gammill Family of Marble Falls, Texas, and Oklahoma City, Philanthropist

Jill & Andy LeBlanc of New Orleans and Houston, Fundraisers

Benjamin D. Cowley Jr., M.D. of Oklahoma City, Physician

Carolyn Morris of Southlake, Texas, Volunteer

Patti Ruffin of San Antonio, Volunteer

Norm Sereboff of Dallas (posthumous award), Lifetime Achievement

## Karyn and Jerry Waxman: On a Mission to Continue the Momentum

When Karyn Waxman was diagnosed with PKD in 1999, she saw little reason to hope for a future without PKD. Today Karyn and her husband Jerry are encouraged by the progress they've seen, and give much of the credit to the PKD Foundation.

"The PKD Foundation truly fulfills its promise to educate, support, advocate, and focus on essential research to improve the quality of life for its constituents," says Karyn. "We have met the most wonderful, caring researchers, doctors, and PKD staff members through the years who not only believe in the PKD cause, but routinely go the extra mile to stay on track to help fulfill the organization's mission to end PKD."

The Waxmans are members of all three of the Foundation's Giving Societies – Annual, Lifetime and Legacy Giving. They host one of the most successful Foundation events, the Liberty Mutual Insurance Invitational Driving Home a Cure for PKD, netting nearly \$1 million to date for the Foundation. Karyn has served as the Memphis Chapter Coordinator since 2001 and was a board member from 2006-2012. Jerry is a current board member, and together they've worked tirelessly as volunteers, fundraisers, and advocates in Washington, D.C. over the years.

"It is also important because the PKD community needs this support," says Karyn. "PKD research is terribly under funded by both the private and government sectors compared to less prevalent but better known diseases. We believe that our contributions will help the PKD Foundation maintain and continue the momentum that is currently driving us towards treatments and a cure sooner rather than later."



"The PKD Foundation truly fulfills its promise to educate, support, advocate, and focus on essential research to improve the quality of life for its constituents."

– Karyn Waxman

### Other Ways People Gave

**TRIBUTE GIVING: 848** loved ones were honored with gifts totaling **\$392,518**

**GIFTS OF APPRECIATED STOCKS OR BONDS \$192,553**  
in securities gifts were transferred to the Foundation

**WORKPLACE GIVING:** More than **\$206,528** in donations were made through **149** employers during United Way, Combined Federal Campaign, State Employee Charitable Campaign and other workplace campaigns

**MATCHING GIFTS: 148** generous companies doubled or tripled donations from their employees, giving more than **\$388,404**

**VEHICLE DONATIONS: 29 cars** were donated by people designating the funds to the Foundation, totaling gifts of **\$16,038**

**GIVING TUESDAY: 94 gifts** totaled **\$8,475** to help fund a day of research.

# Volunteer Leadership



Chapter and Walk Coordinators with PKD Foundation staff at Leadership Conference.

Volunteers are the backbone of the Foundation. We rely on them to lead Chapters, organize their local Walk for PKD and other fundraising events, and support people in their communities impacted by PKD.

**61**  
Chapters

**238**  
Chapter events

**2,300**  
volunteers

**11,630**  
hours

A value of  
**\$268,304**



Jean Sommer, St. Louis, Mo., Chapter and Walk Coordinator, is one of the Foundation's volunteers who brings the Foundation's mission to life in her local community.

Jean first learned about her PKD and related PLD (polycystic liver disease) in 2002. She's accepted her PKD and PLD and made a conscious decision to have a positive outlook and enjoy life. Leadership training led her to opportunities to get more involved with the Foundation by volunteering as a Walk and Chapter Coordinator — work that's proved therapeutic for Jean.

"I get great satisfaction out of being a coordinator and sharing information with others that wasn't so readily available to me when I was diagnosed. I'm inspired by the concerted efforts of the teams to raise awareness of PKD and drive donations to help find a treatment or cure." — Jean Sommer

# Meet the Team

Thirty-plus years into leading the fight, we remain the only organization in the United States dedicated to ending PKD. Our staff brings a range of experiences to the Foundation, but one thing unites them: a passion for their work. In February, the Foundation welcomed new Chief Scientific Officer David Baron, Ph.D., whose extensive background in biomedical sciences and drug development serves him in his leadership role in guiding the Foundation's research strategy. Dr. Baron received a kidney transplant in 2009 as a result of PKD, so he understands first-hand the urgency to find treatments and a cure to ease the pain of those affected by this disease.



*Jackie Hancock, Jr., CFRE  
CEO*



*David Baron, Ph.D.,  
Chief Scientific Officer*

## Leadership Team

**Jackie D. Hancock, Jr., CFRE**  
Chief Executive Officer

**David Baron, Ph.D.,**  
Chief Scientific Officer

**Angela Connelly, MBA**  
Chief Marketing and  
Communications Officer

**Ray Smith, CPA, MBA**  
Chief Operating Officer  
and Chief Financial Officer

## Board of Trustees

(2015-2016 term)

**Benjamin D. Cowley, Jr., M.D.**  
(Chair)

**Frank Condella Jr.**  
(Immediate Past Chair,  
Vice Chair)

**Fran Towey** (Treasurer)

**Anne Ryan** (Secretary)

**Paul T. Conway**

**Lisa Guay-Woodford, M.D.**

**Michele Karl**

**Klee Kleber**

**Andrea Kringstein**

**Brock Nelson**

**Dwight Odland**

**Craig Ramseyer**

**Julia Roberts**

**Jeffrey Rona**

**Terry Watnick, M.D.**

**Jerry Waxman**

## Scientific Advisory Committee

**Terry Watnick, M.D.** (Chair)  
University of Maryland School  
of Medicine

**Benjamin D. Cowley Jr., M.D.**  
(Past Chair)  
University of Oklahoma  
Health Sciences Center

**Stefan Somlo, M.D.** (Vice Chair)  
Yale University School of Medicine

**John Bissler, M.D.**  
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Health Sciences Center

**Alessandra Boletta, Ph.D.**

**Iain Drummond, Ph.D.**  
Massachusetts General Hospital  
Harvard Medical School

**Ben Margolis, M.D.**  
University of Michigan  
Medical School

**Michal Mrug, M.D.**  
University of Alabama  
at Birmingham

**York Pei, M.D.**  
Toronto General Hospital  
University Health Network

**Ronald Perrone, M.D.**  
Tufts Medical Center

**Richard Sandford, Ph.D., FRCP**  
University of Cambridge  
Cambridge Institute of  
Medical Research

**Darren Wallace, Ph.D.**  
University of Kansas Medical Center

**Angela Wandinger-Ness, Ph.D.**  
University of New Mexico  
Health Sciences Center

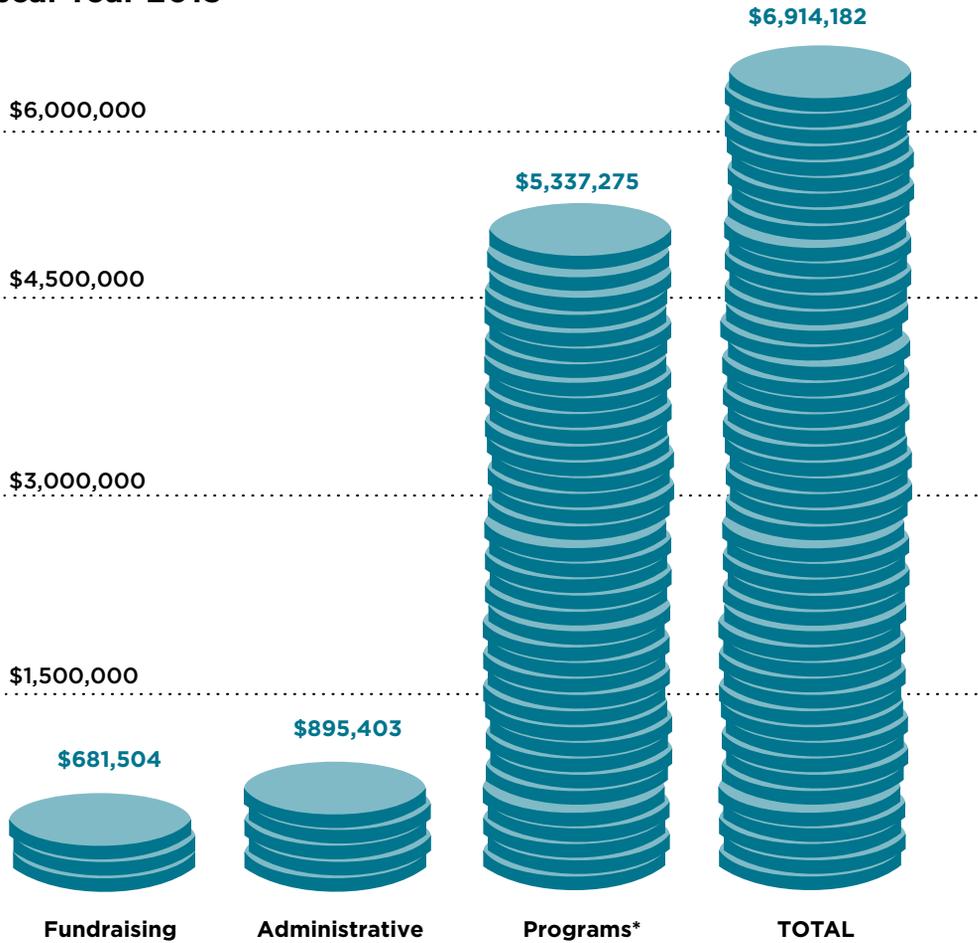
# Thank You!

Thank you for an incredible year. Without you, we wouldn't have been able to accomplish the highlights we've shared with you. We look forward to achieving more together in the future.

# Our Financials

## Where Your Money Went

Fiscal Year 2015



**\*PROGRAMS INCLUDED:**

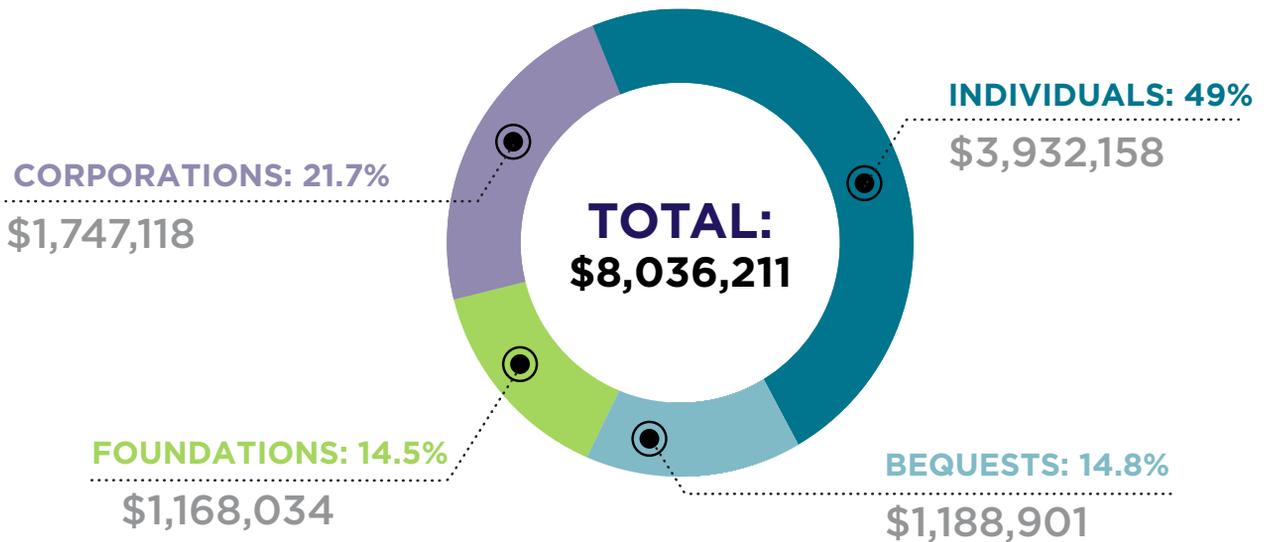
Research: \$2,502,278    Education & Support: \$1,657,058    Awareness & Advocacy: \$1,177,939



of every dollar goes to research, education, advocacy, support or awareness.

	FISCAL YEAR 2014	FISCAL YEAR 2015
Research	\$2,495,467	\$2,502,278
Education & Support	\$1,734,481	\$1,657,058
Awareness & Advocacy	\$1,320,102	\$1,177,939
Administrative	\$967,369	\$895,403
Fundraising	\$761,923	\$681,504
<b>TOTAL</b>	<b>\$7,279,342</b>	<b>\$6,914,182</b>

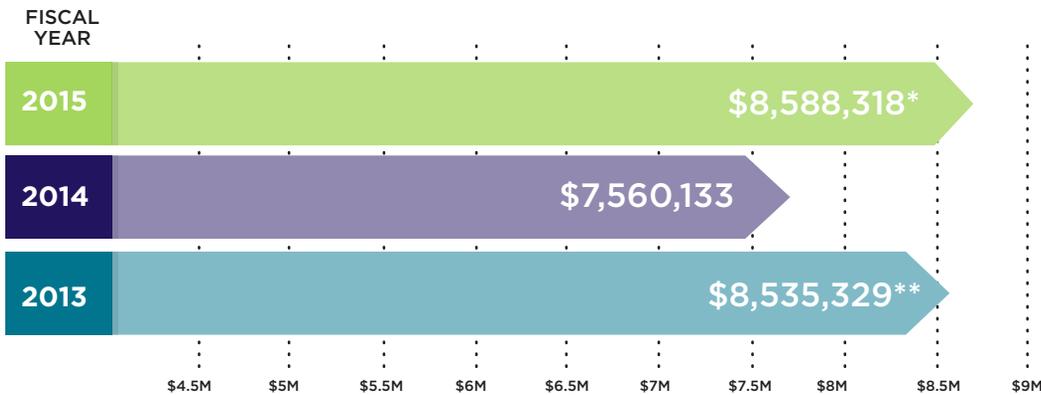
## Where Our Money Came From



Please note: The above revenue figures do not include in-kind gifts.

## Annual Revenues and Financial Position

### Annual Revenues



Please note: Annual revenues are presented on a cash basis and include in-kind gifts.

\*Total revenue in fiscal year 2015 includes a single bequest of \$1 million

\*\*Total revenue in fiscal year 2013 includes a single bequest of more than \$1.6 million.

### Financial Position: June 30, 2015

<b>ASSETS</b>		<b>LIABILITIES</b>		<b>NET ASSETS</b>
\$6,476,331	—	\$941,887	=	\$5,534,444



View our audited financial statements at [pkdcure.org/2014-15-audited-financial-statements](http://pkdcure.org/2014-15-audited-financial-statements)

**OUR MISSION** Promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.

**OUR VISION** One day, no one will suffer the full effects of polycystic kidney disease.



**PKD FOUNDATION**  
Polycystic Kidney Disease

pkdcure.org  
1.800.PKD.CURE